SUMMER 2008 ISSUE 224

link

The magazine for people with
hydrocephalus and spina bifida

Transition supplement

see more on pages 13-20

INSIDE THIS ISSUE

association for
spina bifida
hydrocephalus
ability beyond disability
TM

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You could be up, up and hopefully far away as a winning sponsor in one of our annual ASBAH balloon races.

For a small cost, which goes to help people with spina bifida and hydrocephalus, you can back a balloon to travel the furthest in one of our 10 races around the country. The winning balloon will win its sponsor a case of champagne.

But you'd better have the wind at your backs – previous winners' balloons have made it to Germany, Belgium and the Netherlands.

ASBAH holds 10 races a year. The next three races in 2008 are as follows:

St Swithins	**14 July 2008**
Grand Summer	**1st August 2008**
Autumn Extravaganza	**1st September 2008**

For more information call our telephone fundraising team on 01733 421334

link

the lifestyle magazine for people with hydrocephalus and spina bifida

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Gill Winfield writes

Welcome to the latest edition of *Link* magazine which we hope you'll have time to enjoy while you're outside, soaking up the sunshine. (I'm keeping my fingers crossed on that one!)

There's certainly plenty inside to keep your interest, whatever your age or situation. We're particularly pleased to dedicate eight pages to Transition – from adolescence to adulthood.

It can be tough being a teenager, but it's sometimes harder if you have a disability or learning difficulty. So we've talked to several experts in a range of fields to bring you some good advice and directions on where to go for more information. There is plenty of help out there if you know where to look and who to speak to.

Of course we're always keen to hear from our readers and if you have any useful advice about Transition please get in touch by email or write to us at the usual address.

As well as the usual news and fundraising round-ups we look at two holistic clinics in London which are providing first class treatment for patients with spina bifida.

There's a special feature by Nurse Joanna Smith who is working on a study about living with a child with spina bifida. We also speak to reader Helen Barnett who was prompted to take a test for latex allergy after reading our feature in *Link* 222.

So all in all it's another bumper issue. Happy reading.

Gill Winfield
Marketing and Communications Manager
gillw@asbah.org

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ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life

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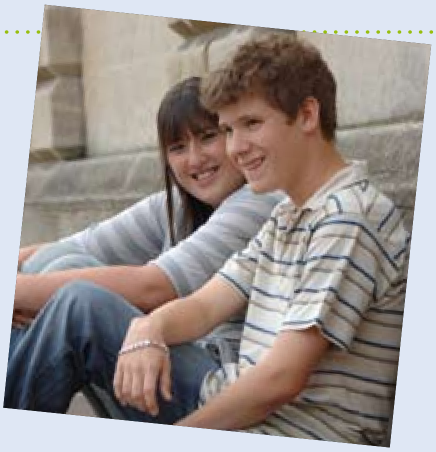
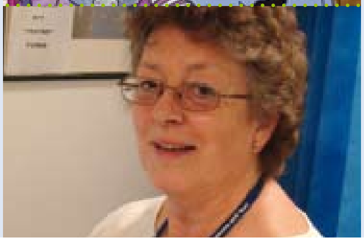




Japanese visit

Three Japanese nursing professors visited ASBAH to learn more about its vital work.

Yoko Noda and Hisako Adachi from Gifu University and Toshiko Ono from Kawasaki City College of Nursing, spent a day with key members of staff to learn more about ASBAH and the research it is currently involved in.

The visitors were particularly interested in sexuality and menstruation in girls with spina bifida, as they are currently undertaking a research project in this area.

ASBAH's senior adviser on health and policy issues, Rosemary Batchelor, said: "Receiving a visit from three professors who had travelled half way around the world to find out more about ASBAH was certainly exciting. It was interesting to find out about the work the nursing professors do in Japan and learn how they perceive spina bifida and hydrocephalus."

After visiting the office in Peterborough, the nursing professors went on to the Chelsea and Westminster Hospital, in London, where they met with Dr Richard Morgan.

Dr Morgan runs the country's only holistic treatment clinic for adult patients with spina bifida and/or hydrocephalus at London's Chelsea and Westminster Hospital.

On page 30 we talk to Ann Wing from the Chelsea and Westminster Hospital's clinic to learn more about its work.

A Postcard to Beijing

It's not every day you get the opportunity to attend one of the biggest ceremonies in the world, but nine-year-old Gareth Picken received an invitation to take part in this summer's Paralympic Games Handover Ceremony in Beijing, China, after he won Blue Peter's 'Postcard to Beijing Competition'

Gareth, who has spina bifida and hydrocephalus, was judged as one of two overall winners. He will now take part in the ceremony which will take place in front of 91,000 people and a worldwide audience of TV viewers!

To win, Gareth had to write a postcard to an imaginary child in Beijing. He had to tell them why he was excited about the Olympic or Paralympic Games and about something he loves doing, along with a photo of him doing it.

Gareth's postcard message read:

POSTCARD

'Dear friend,

I'm really excited about the Paralympics in China because it brings together people from all over the world for a special time of friendship and sport. All people, disabled or able bodied, can enjoy this brilliant event.

One day, I would love to be in the Paralympics and represent my country. I'm trying to be a strong gymnast especially on the bars. Last July, I was the first wheelchair gymnast to take part in the World Gymnaestrada. I want to show what disabled kids, like me, can do. It's going to be fun.'

Congratulations Gareth!

Area adviser funding extended

Eastern region staff breathed a huge sigh of relief when two county councils agreed to extend funding of two ASBAH area advisers.

Earlier this year both Lincolnshire (LCC) and Northamptonshire County Council (NCC) signed new service agreements, together worth almost £50,000, to keep Sharon Lapsley and Linda Knight in position.

Sharon joined the ASBAH team in June 2005 as the new part-time adviser for Northamptonshire – an area which hadn't had a permanent adviser for four years – after NCC agreed a three-year funding contract.

Lincolnshire County Council has also agreed to follow on the two year agreement which covers part-time adviser Linda Knight with a new 12 month service level agreement.

Now David Isom, Eastern Region manager, is justifiably thrilled – and relieved – that the support has been extended.

"It was fantastic news," he said. "Sharon and Linda have done so much work in their areas and it is a relief that we don't have to apply elsewhere for funds to keep them in position. We are delighted that we continue to have the support of both county councils."

"I have to admit that preparing for the NCC application was very stressful but we did have contingency plans in place just in case we were turned down.

"Service users from both counties will really value the funding and will continue to access ASBAH's unique adviser services."

Anne Beadle, Contracts Officer for LCC, said: "Funding for ASBAH was agreed because the Council wished to continue to support a programme of public awareness of spina bifida and hydrocephalus and to provide people and their families with an information and support service."

"I am obviously very pleased that ASBAH has received the funding for another two years from Northamptonshire County Council. It will enable me to continue working with families and individuals and it gives them the security of a local point of contact when they feel they need advice and support.

"Since I took up the position I have been asked to support people with various issues such as claiming benefits, obtaining equipment for both housing and mobility purposes, and I give talks to schools. The funding will allow me to maintain the relationships I have built up and hopefully create new ones."

Sharon Lapsley, adviser for Northamptonshire

Showcase for ASBAH services

For the second year running, ASBAH had a stand at Naidex, at the NEC in Birmingham, and received over 350 visitors over the three-day event.

Naidex is one of the biggest disability product shows in the UK. Having a presence at the exhibition provided an opportunity to spread the word about our services, the helpline and our information and publications, to both professionals and service users. Adults with spina bifida or hydrocephalus were able to renew their acquaintance with ASBAH, some after being out of touch for some years. Parents and adults with the disabilities were pleased to find us at the show: "It's made it worthwhile coming," was one parent's comment, on discovering that one of our regional offices is very close to where they live and that ASBAH could help with some issues their daughter was having.

The helpline team were also able to gather more information from other exhibitors including details on Canine Partners (who provide highly trained assistance dogs to help people with disabilities lead more independent lives).

There was also all the latest in adapted clothing, continence products, accessible holidays from a variety of providers, in fact pretty much everything to do with daily living with a disability. All the information will be added to the helpline's knowledge base to help with future enquiries.

Naidex takes place each year at the end of April/beginning of May and tickets are free, so why not make a date to visit us there next year – we've already booked our stand!

Making antenatal care better

A symposium covering the viewpoints of parents, obstetricians, radiologists, neurosurgeons and fetal-maternal consultants looked at how antenatal care can be improved after pre-natal diagnosis of spina bifida or hydrocephalus.

The event at the Royal College of Gynaecologists and Obstetricians, in London, was organised by ASBAH after our medical committee became aware of the great variation in care offered to women who faced a decision on whether to continue with a pregnancy.

There was common agreement that the parents' decision needed to be based on informed, impartial information and advice which must be evidence-based. Unfortunately, surveys have shown that many patients feel medics are anti-disability, and parents don't always get the time and information they need to make an informed choice on how to proceed.

It was acknowledged that it is extremely difficult to give an accurate picture of how a neural tube defect, or hydrocephalus, might affect an individual child's future and professionals need to be honest about these uncertainties and how the initial prognosis could change – with a better or worse outlook.

The audience of professionals heard personal experiences from two women (with different outcomes to their pregnancies), which highlighted good as well as bad practice.

Speakers were able to share good practice during the symposium, including:

- *Signposting to ASBAH and ARC (Antenatal Results and Choices) and the Child Bereavement Charity*
- *Making sure patients receive written reports of consultations*
- *Continuity of care – including a specialist midwife*
- *Multi-agency approach to care*
- *Care of the father*
- *Communication between professionals, and between professionals and patients*
- *Time and compassion, from professionals, to parents in this situation.*

ASBAH will be producing a report, based on the symposium, with further input from other sources, in order to spread good practice.

ASBAH would like to thank Codman, who supported the symposium with an educational grant.

New folic acid awareness campaign starts this summer

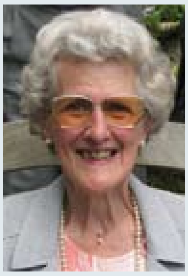
It's 10 years since the end of the Health Education Authority's campaign to promote awareness of folic acid amongst professionals, and women of childbearing age.

But this summer there will, at last, be a new initiative to remind women of this important message, even more necessary now that fortification of flour with folic acid has been delayed for at least another year.

An updated folic acid leaflet will shortly be available from the Department of Health and a series of articles will be placed in women's magazines, featuring ASBAH families who will be helping put the information across in a positive way, so watch out for their stories during the summer months.

Ros Scott

By Jo Baxter, North & West Yorkshire ASBAH



It is with great sadness that North & West Yorkshire ASBAH announced the sudden death of one of their Trustees, Ros Scott.

Before becoming a trustee Ros was the first fieldworker in our area employed by national and part funded by Leeds and Bradford ASBAH.

Ros was held in very high regard by those many members who benefited immensely from her sympathetic help and support when they had problems and challenges.

The committee and national ASBAH found her to be an extremely conscientious and hard working member of the team who we all came to know as a friend.

Ros joined us in 1977 and retired in 1992; she became a trustee in 1994. This was not just a nominal role as Ros attended many committee meetings and always took an interest in the members.

When the association was struggling for funds she and her husband Frank opened their garden for afternoon tea. Only a matter of weeks before her death she wrote to the committee and members to congratulate them on all that was happening within the association.

After her retirement Ros was able to enjoy her hobbies of her garden, opera, amateur dramatics, walking and conversational French.

Ros enjoyed her holidays and entertaining her many friends and she was an extremely talented and welcoming hostess.

She leaves a husband, Frank, sons Mark and Jonathan and grandchildren Frances, Hannah and Hayden, to whom we extend our sympathies.

Friend and colleague, Joan Pheasant, Northern Regional Manager said: "I remember Ros fondly, she was a lovely person who always had time for those she came into contact with, she had a lasting impact on many lives. I will miss our lunches together and friendship she showed."

Latex allergy – Helen's suspicions prove true

Our recent feature about latex allergy set alarm bells ringing for one *Link* reader.

Helen Barnett, who has spina bifida, first experienced swelling of the mouth after dental treatment several years ago, which only occurred when the dentist wore gloves.

More recently her eyes had swollen after eating avocados, chestnuts and bananas, which had never caused problems before.

But it wasn't until she read about the condition in *Link* that she suspected she may be allergic to latex.

Helen, who works in local government in London, said: "After reading the article I went on to the ASBAH website to learn more about latex allergy and the products and foods which could trigger reactions in sufferers.

"Suddenly everything began to make sense so I decided to be tested. After having the pin prick test patients are usually asked to wait for 30 minutes to see if their skin has reacted to the substance. Mine reacted almost immediately and the doctor confirmed that I am extremely allergic to latex.

"I had experienced problems during several operations although no-one ever suggested that I could have an allergy.

"During an endoscopy my lower body swelled up like a balloon. My mother also recalls an incident when I was a child when I had an IVP contrast test where dye was injected into the body to help doctors examine my kidneys and bladder. Apparently I nearly died twice."

Helen said she is now very careful about what foods she eats and the products she uses to prevent allergic flare-ups.

"What I find incredulous is that people who have spina bifida aren't tested for latex allergy, because it is so common, particularly among people with the condition," she said.

"But it is a huge relief to know what is wrong with me so I can try to limit reactions. I also wear a medical bracelet to make sure that medical staff are aware if I ever need emergency treatment."

The transition from adolescence to adulthood, including independence, responsibility and positive outlook, was top of the agenda for service users and carers at ASBAH's Eastern Region, Looking Ahead with Hydrocephalus conference, which took place in Nottingham on the 14 May.

Looking Ahead with Hydrocephalus

The conference, which was aimed specifically at 12 to 25 year olds and sponsored by the Roald Dahl Foundation, attracted plenty of interest with 62 delegates attending to hear the professional speakers and visit the trade and information stands.

The conference opened with an introductory overview of hydrocephalus from Dr Roger Bayston. Dr Colin Dunkley continued with a discussion of the medical management of epilepsy. This was followed by Dr Andrew McEvoy, who spoke about the surgical management of epilepsy.

Delegates later heard Dr Hugh Richards explain the shunt registry and Dr Catherine Loveday give a neuropsychological perspective of hydrocephalus.

The day also included an interactive session based on Naomi Marston's research into employment and higher education opportunities for people with hydrocephalus. This session was particularly popular with the teenagers at the conference.

Feedback indicated that the conference was a great success. Matthew Bottoms and Daniel Hulatt from Bedford said, "We learnt more today than we have the rest of our lives."

Jenny Cooper from Lincolnshire agreed, "I am so glad I came, it was a wonderful day and my Mum and I have learnt so much."

Event organiser, David Isom, said: "It was a very informative day and we were delighted that so many people were able to attend.

"I'd like to thank everyone who helped to make the event a success, including all the staff at the East Midlands Conference Centre."

There are about 50 million mobile phone subscribers in the UK and it is estimated the average mobile phone user will replace their handset once every 18 months.

Less than 20% of all unused mobile phones in the UK are currently recycled and estimates state that close to 90 million phones are hiding in drawers and cupboards across the UK (11250 tonnes) - these weigh almost six times as much as the London Eye!

ASBAH can turn these phones into much needed cash so don't forget to use the envelope supplied in the last edition of *Link* to recycle you old mobile phone.

To request an envelope please email cerysl@asbah.org or call our helpline on 0845 450 7755.

ASBAH Champion Celebrates 80th Birthday

One of ASBAH's longstanding donors, Mary Woolman, celebrated turning 80 by holding a birthday bash for her friends and family raising an impressive £252 for ASBAH.

ASBAH's Regional Manager, David Isom, was invited to the celebration where guests were asked to donate to ASBAH rather than buy birthday gifts for Mary who found out she had spina bifida 20 years ago.

He said: "It was great to attend Mary's party and join in the celebrations. Mary has been involved with ASBAH for many years and has actively raised money and awareness within her local community.

"The party was great fun. There was plenty of food, music and singing and guests were treated to a delicious birthday cake."

A keg full of cash for ASBAH

ASBAH's coffers received a generous £500 boost when organisers of the Alton Winter Beer Festival made a donation from its profits to ASBAH.

More than 1,000 people from across the country headed to the Maltings Centre in Hampshire on 16 February for this year's festival.

Revellers downed 4,000 pints of beer between them whilst enjoying lunchtime entertainment from local jazz band, Grandpa Bells, or dancing the night away with Doctor Dawson's Boogie Band.

The sell out festival is not only organised to quench the thirst and tickle the taste buds of beer lovers but donates all the profits to charity and this year ASBAH was lucky to be chosen as one of the beneficiaries.

Organiser, Ysanne Legg, said: "The winter festival was another great success. Since we began in 2002, we have raised more than £40,000 for charity and hopefully our donation to ASBAH can really make a difference to the lives of local people with spina bifida and or hydrocephalus."

If you fancy sampling the finest ales yourself head to next year's festival on 31 January 2009.

Caroline Finch brews up charity boost

A coffee morning and raffle, hosted by Caroline Finch, in Parkstone, Bournemouth has raised £136 for ASBAH.

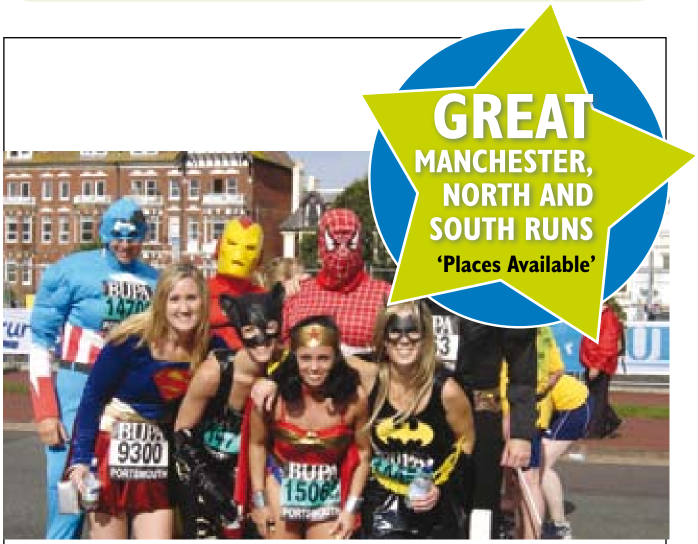
The fundraising event, held on 17th March, was attended by more than 20 local people of all ages.

Guests enjoyed a very social lunch and the chance to purchase Caroline's homemade greeting cards. Raffle prizes included a variety of Easter eggs, wine and photo frames.

Caroline said, "Having made my own cards for years I thought this would be a great chance to sell them for a good cause.

"I have had hydrocephalus my whole life. ASBAH has provided me with a lot of information over the years so I was keen to do some fundraising that would benefit people like myself."

The coffee morning was such a success Caroline is continuing to make her cards and sell them to friends and family, with all the profits going directly to ASBAH.



GREAT MANCHESTER, NORTH AND SOUTH RUNS
'Places Available'

RUN for ASBAH

ASBAH is a registered charity that provides advice and support for over 15,000 babies, children and adults with spina bifida and hydrocephalus.

We need your help so we can continue to promote awareness, help families and carry out vital research.

For sponsor forms, please contact:
Ian Morley, ASBAH, 42 Park Road,
Peterborough PE1 2UQ
Tel: 01733 421328
Email: ianm@asbah.org
www.asbah.org

association for spina bifida hydrocephalus
ability beyond disability

Registered charity no. 249338

Team work name of the game at Great Manchester Run

The 10km event, which this year was held on Sunday 18 May, attracts more than 25,000 runners each year.

Ian Morley, an ASBAH event fundraising officer, ran the race last year and this year was back for more along with his trusted running buddy, Emma Hine. Emma and Ian tether themselves together to run the race as it can be quite daunting for Ian to run alone in a large crowd because he is visually impaired.

The pair live 150 miles apart meaning training together is not an option, but they trust each to do their bit and make sure they're ready to race on the day. Ian's training consisted of getting up at 6am to run one kilometre before going to work. He increased this to three kilometres a few weeks before the race.

Unfortunately, Ian suffered a painful injury to a toe after tripping on a slab in his garden a week before the race meaning that he could no longer train. As a result, Ian was not able to run for all of the race, but instead the pair power-walked their way around the course. Amazingly, they completed the race in one hour and 42 minutes; this is only a few minutes longer than they managed at full speed last year!

Ian said: "I am so pleased to have been able to raise £800 for ASBAH, with more donations continuing to be made through my website, ***www.justgiving.com/bigfella***"

Emma Hine has raised a substantial amount of money for ASBAH over recent years. Emma's seven-year-old son, Lewis, has hydrocephalus and the Hine family have received a lot of support from ASBAH.

Ian and Emma weren't the only ones supporting ASBAH in Manchester. Matt Johnson, a PE teacher from Bolton also participated along with his friend, Peter Lomax, who was there to give moral support. Matt who was diagnosed with hydrocephalus last year said: "I was delighted to be able to raise money to help people with hydrocephalus and spina bifida. I really enjoyed taking part in the event, and I was pleased to finish in a decent time. It was a great day."

Another ASBAH fundraiser at Manchester was Tom Gammell from Huddersfield who was raising money for a friend who benefits from ASBAH services. Tom said: "I had a really good day - the support from the crowd was fantastic and made a big difference to us all. I wanted to make sure that the wonderful services provided by ASBAH remain available." Tom completed the course in 51 minutes and has raised a fantastic £485.00. His Just Giving web page can be viewed at ***www.justgiving.com/tom-gammell***

Ian Morley and Emma Hine

Peter Lomax and Matt Johnson

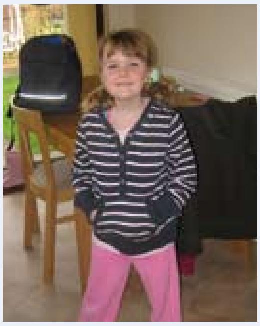
The 2008 London Marathon

An incredible 35,000 runners descended on England's capital on the 13 April to take part in the world famous London Marathon.

Andrew Wright, a dedicated ASBAH fundraiser, was there to add yet another race to his impressive repertoire and raise £800 for the charity.

Andrew has been running for ASBAH ever since the birth of his daughter Katie, now seven, who has hydrocephalus. Katie was born ten weeks premature and had a VP shunt fitted at four weeks.

The family received a great deal of support from ASBAH from the outset, which is why Andrew dedicates so much time and effort to raising money for the charity.



Andrew's daughter Katie

Andrew, from Stilton, near Peterborough, has run in various events across the UK, but this is the first time he has taken part in the London Marathon.

Sixteen weeks before the race, Andrew began a rigorous training schedule in preparation, using Runners World, a magazine and website that provides help and advice on how to train for long distance races. He ran between 14 and 20 miles once a week.

On the day, Andrew completed the race in four hours 14 minutes and 49 seconds. He said: "My time was ok but I was a bit disappointed. It wasn't what my training suggested I would do it in.

"I was hoping to finish in under four hours but I was hindered throughout the race by the thousands of other participants who were walking - it was very difficult to pass them."

Andrew Wright

Andrew believes it is becoming increasingly difficult to get sponsorship, due to the amount of people asking to be sponsored, particularly in workplaces.

But while he was looking for sponsorship, he used the opportunity to talk to people about hydrocephalus, and the work that ASBAH does.

Andrew said: "ASBAH have given a tremendous amount of support to our family and we are so grateful for all that they do for us, they are a wonderful charity."

International projects get a helping hand from ASBAH

ASBAH is working in partnership with the International Federation for Spina Bifida and Hydrocephalus (IFSBH), to provide medical help in the developing world.

So far, ASBAH's fundraising department has applied for grants to seven UK Trusts, but Helen Dow, project co-ordinator, explained that the funding which has been applied for will not affect ASBAH's work in the UK.

She said: "We have approached Trusts and Foundations which would not be able to give to our UK projects because we do not fit their criteria."

While the new partnership has several projects in the pipeline, it is initially concentrating on raising funds for life saving surgery to treat hydrocephalus in babies and infants at the national referral hospital in Mbale, Uganda.

The cost of each operation is £400 and ASBAH has committed to funding 25 surgeries at a cost of £10,000.

Helen explained: "The evidence the IFSBH has gathered since working in Uganda suggests a higher incidence of spina bifida than the global average.

"This is probably caused by the high incidence of displacement and overall low level of food security. Other common causes of hydrocephalus include malaria and meningitis infections in infants."

In Uganda, where urgent access to neurosurgical care is not available, shunts are not the first option for treating hydrocephalus

Surgeons prefer to perform an ETV/CPC – a combined endoscopic third ventriculostomy and choroid plexus cauterisation, a procedure that involves making an opening in a brain ventricle to allow the fluid to escape whilst also reducing the amount of CSF that is produced by the brain.

Helen said: "The hospital prefers to carry out ETVs where possible because, for many patients, getting to the hospital can means a two or three day walk.

"If a shunt is used, the patient will have difficulty getting back to the hospital quickly if the shunt becomes infected or fails."

Helen, who is working in close partnership with Lieven Bauwens from the IFSBH's headquarters in Brussels, is also developing two other applications.

One is for ETV surgical equipment which is needed for work in Tanzania and the second to fund training in neurosurgery for hydrocephalus, for the only female Nneurosurgeon in Bangladesh, who will travel to Uganda for the training.

She added: "ASBAH is very pleased to support people with spina bifida and/or hydrocephalus in developing countries, it is an exciting new area of work for us and we are looking forward to developing our partnership with the International Federation for Spina Bifida and Hydrocephalus."

KEY POINT

- ASBAH's international partnership
- Accessing £10,000 funding to support surgeries for infants and babies diagnosed with hydrocephalus

The CURE Children's Hospital in Mbale, Uganda, has become the main referral hospital for spina bifida and hydrocephalus treatment.

It is also the national centre of excellence on the alternative to shunt surgery for hydrocephalus - ETV - and hospital staff work closely with Katalemwa Cheshire Homes hospital in Kampala to provide post-operative rehabilitation for the children who have been treated.

The hospital performs over 1,000 surgeries a year to treat hydrocephalus and spina bifida and runs 30 satellite clinics for follow up appointments.

As well as the surgical treatment, other services offered are: continence management by specialised spina bifida nurses; the provision of the vitamin folic acid to all mothers who are seen by the hospital; and a multidisciplinary team to see each child with the conditions.

The surgeons also run a training programme on the ETV technique for neurosurgeons from other countries so that skills are shared with other African and Asian surgeons.

STAR supporters

Shan Owen organised a spectacular charity ball in memory of her mother and raised more than £6,000 for ASBAH in the process.

Around 100 people from across England and Wales descended on Llandudno's elegant Imperial Hotel in their best evening attire on 19 April for a glamorous evening of entertainment.

The ball was held in memory of Shan Owen's mother Mair Owen who had hydrocephalus and passed away last year.

Guests were treated to a host of entertainment including a raffle, auction and dancing.

Bids quickly escalated for an array of items including: rounds of golf, an overnight stay at the Imperial Hotel, tickets for the Sleeping Beauty on Ice show, and, as if organising the ball was not enough, Shan also auctioned off her services as a hairdresser for an entire year for one lucky person.

ASBAH patron, Danny Mills, kindly donated a signed shirt and football, along with two free VIP tickets to a football match and entrance to the players lounge after the match. These prizes alone raised more than £400.

Another highlight was the delicious meal prepared and served by the Welsh National Culinary team who regularly prepare food for royalty.

The event was an outstanding success largely down to Shan's enormous efforts. The six months preparation included organising the evening, sourcing prizes and travelling across North Wales selling tickets... raising awareness of ASBAH at the same time.

"I wanted to increase the profile and understanding of hydrocephalus and the work of ASBAH as well as paying tribute to my mum, who would have been 60 this April," explained Shan.

During the three years she cared for her mother Shan received a lot of support from ASBAH. "There seemed to be limited knowledge on the condition from other sources but ASBAH were always a great help," said Shan.

"Everything ran so smoothly on the night, it was absolutely amazing, six months of planning and hard work really paid off. I especially enjoyed being able to dress up and enjoy myself."

ASBAH Webshop opens for business

Your online shopping could earn money for ASBAH!

The new ASBAH Webshop provides a free entry point to lots of your favourite online stores, but the best part of using the ASBAH Webshop is that whilst buying from these online retailers, you automatically raise money for ASBAH.

Simply click on the Webshop icon on the homepage of the new ASBAH website and you will directed to a shopping portal where you can browse more than 150 shops by categories such as fashion, travel and electrical or by the retailer's name.

Most large retailing groups with shops nationwide are in the system, including huge brand names like Tesco,Vodafone, Curry's and John Lewis, as well as Amazon. You can even raise money for ASBAH by booking your next holiday or taking out new car insurance.

ASBAH's Director of Fundraising, Colin Roberts, says: "The ASBAH Webshop is part of our continued fundraising efforts here at ASBAH. This fundraising applies to all our stakeholders – anyone can use the Webshop. Users can take advantage of online bonuses and discounts whilst raising money at the same time – it's a win win situation."

So, next time you are stocking up on groceries, books, the latest DVDs or fashion accessories, why not shop through the ASBAH Webshop. Every purchase helps ASBAH to help those with spina bifida and hydrocephalus.

Getting to know the neighbours

ASBAH has been based in the city of Peterborough since moving its headquarters from London in 1990.

But do the people of Peterborough know there is a national charity on their doorstep?

According to a recent study of neighbourliness conducted by the BBC, more than one in five people (22%) believe our neighbourhoods have become less friendly in the last five years.

So a team of ASBAH staff gave up a Saturday in May to visit Peterborough's Queensgate Shopping Centre to get to know their neighbours and raise awareness of ASBAH and the work it does.

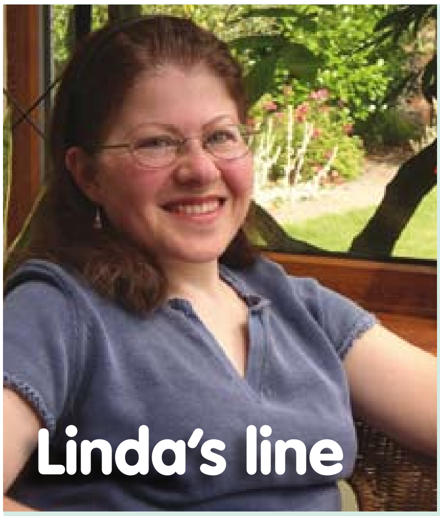
The team set-up an information point within the shopping centre and enticed shoppers with a tombola.

They offered information on a range of topics that shoppers might have found useful, including folic acid, an issue which all women of child bearing age need to be aware of.

The day was a big success. If the shoppers of Peterborough weren't aware of ASBAH, they will be now!

Link Editor, Gill Winfield, who lives in Peterborough, went along for the day. She said: "We had a steady stream of visitors to our stand and there were several who knew someone with the disabilities or had a family member affected but didn't know about ASBAH and how we can help.

"We were also delighted by the generosity of shoppers, as we collected over £562."



Linda's line

If I ever moaned in the past about disability awareness at work, I take it all back. Granted, I did occasionally have to turf people out of my parking space, and I never quite managed to get exclusive rights to the disabled toilet, but in general I did pretty well.

However, disability awareness has gone to hell in a handcart following our recent office move. I was initially lulled into a false sense of security by the assurance of a parking space near the back door, but I soon discovered that the back door was up a short flight of narrow brick steps over which the local pigeon population hover in a menacing sort of way (when they're not otherwise engaged in dive bombing the parked cars).

My colleagues are required to use the front door (involving a short walk round the outside of the building on a flat surface, mostly under a portico) whereas I am supposed to use the back door, running the gauntlet of pigeon alley twice a day, as this is considered to be a concession. (Excuse me if I don't sound very impressed).

Even more unhelpfully, whoever designed the car park must have measured out the spaces using a motorised suitcase as that is about the only thing that you could comfortably park in those spaces.

Without wishing to sound ungrateful, an anorexic gnat would have a problem getting out of my car without scraping the paintwork, once the rest of my colleagues are parked alongside, and I am not the only one having difficulty with this.

After several days of having to move at least one vehicle every time I wanted to get into my car, I have been given a temporary parking space somewhere else which has loads more room to get in and out, while the management have a re-think.

In the meantime, with my very handy window seat, I have been making the most of the afternoon car park entertainment. This chiefly consists of watching the general public a) trying (illegally) to manoeuvre their oversized cars in our titchy parking spaces and b) trying to wheedle out of paying the penalty notices dished out by the local parking enforcement officer who does his rounds about 3.30 in the afternoon. Whoever said that pensions were boring?!

Ironically, most of the illegal parkers are just trying to avoid having a longer walk to the leisure centre which is next door to our office, since our spaces are closer than theirs.

Perhaps if their customers parked further away and then walked to the leisure centre, they could get fit for free!

I expend enough effort trying to dodge the pigeons and get up the steps without scuffing my shoes, but I suppose if I wanted a bit more exercise I could always try shooting the pigeons instead. The one that got my car the other day is already on borrowed time….

Specialist Clinic at Great Ormond Street Hospital

Great Ormond Street Hospital (GOSH) in London is a world class hospital dedicated to caring for sick children. Lindy May is an experienced nurse consultant at the hospital who is involved in the care of children with spina bifida and hydrocephalus.

Eighteen months ago Lindy, who has an MSc in neuroscience, set up an out-patient holistic myelomeningocele clinic at GOSH, after realising that the needs of children affected by spina bifida and hydrocephalus could be better addressed through a multi-disciplinary clinic that is not necessarily medically led.

The clinic focuses on the social as well as physical needs of a child. Lindy manages the clinic alongside a specialist physiotherapist and urology clinical nurse specialist. She liaises as appropriate with disciplines such as orthopaedics and social workers.

The clinic runs for one afternoon each month and is available to any child who has received treatment at GOSH. Lindy believes that it is beneficial for families to have to attend as few out-patient appointments as possible, as it can often be difficult to travel.

The children who attend the clinic will have undergone neurosurgery at GOSH and Lindy works closely with the families during this time, alongside the ward team.

The clinic provides an opportunity to discuss the wider issues affecting the child and their family, rather than focusing solely on medical problems. Lindy always points clinic users in the direction of ASBAH and explains the help that the association provides. She discusses how to cope with the initial diagnosis and offers guidance and advice to parents, but refers families to ASBAH for the more chronic issues.

Lindy May

Transition SUPPLEMENT

In this issue, our supplement focusses on the transition period from teenage to adult years. For some disabled young people this can stretch from 13 to 25 years and covers education, medical and social aspects of moving into adulthood.

Contents

Your Transition Plan –
a brief guide for young people

Most transition plans for children with a disability or learning difficulty are first drawn up in Year 9.

The local education department of your local authority will invite you and your parents or carers to attend a review meeting, which must include creating a Transition Plan.

The Transition Plan review meeting is usually held at school and the people who are involved in supporting you as you move into adulthood should also attend.

These may include:

- *Someone from social services, to make sure you get a health and social care assessment if you have health and social care needs*
- *Your local doctor or community nurse*
- *Your teacher(s)*
- *Someone from the Connexions Service*
- *An educational psychologist, to make sure you get the support you need to carry on learning*
- *Anyone else who you would like to support you at the meeting*

Your Transition Plan is all about what you want for your future. Your input into the review meeting is important, and everyone else must listen to what you have to say and keep a record of what you want for your future.

Because you will be asked about your plans for your future, it's a good idea to think about what you want to say before the meeting.

You should use the meeting to find out what services and support you're entitled to and what choices are available to you.

After the review meeting

After the meeting, you and your parents or carers will normally be sent a copy of the Transition Plan. The education department of your local authority must also give a copy to your head teacher, social services and any other relevant professionals and carers.

The education department of your local authority is responsible for making sure that you receive all the support and services that are listed as necessary for you in your Transition Plan.

You should have another review meeting each academic year to update your Transition Plan.

For more information about Transition Plans go to: ***www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/Schools***

Going to University?
Practical advice from Anna Charles-Jones

Anna Charles-Jones is a Learning Support Adviser for the Learning Support Service at Manchester Metropolitan University.

Anna, who has spina bifida & hydrocephalus and is a part-time wheelchair user, attended mainstream school before taking 'A' levels at a further education college in Warwickshire.

She then went to Manchester Metropolitan University (MMU) from 1999 -2002, graduating with BA (Hons) Applied Community Studies. During this time she was also the

continued on next page

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Disabilities Officer at the Students' Union.

Anna is now settled with her partner, Jason, in Greater Manchester and has worked at the university since finishing her degree, first as a clerical assistant, and since December 2003 as Learning Support Adviser for the Learning Support Service ***(www.mmu.ac.uk/lsu)***

Anna took time out of her hectic schedule to give some practical information and advice about what students with a disability should consider when applying for courses, and what support they can expect.

What are the main challenges young people with a disability face when they move towards higher education?

The main challenge they face is becoming more independent, both in terms of study and any disability-related support that they may need.

What should they think about when looking to apply to a university or college?

In the same way as any other student, the most important thing is the subject that you wish to study and where you would like go to university, such as in a big city or a smaller, more rural location. Once you have made a short-list you can then visit each university and start to consider any disability-related issues which may influence your decision, for example, accessible hall accommodation, transport, or whether it just has the right 'feel'.

Is it important to be very prepared and know all the right questions to ask?

If there is anything that you need to know that is very specific to you, it is always worth asking about this at a very early stage e.g. if you need a hoist or if you need adapted accommodation. However, the disability adviser will be able to ask you the right questions to get the information that they need to find out about any support you require.

Where can you go for help?

The disability adviser is always a good place to start if you have a question about a disability-related matter but most universities also have a students' union, advice centre and other 'student services' such as counselling and careers advice, should you need any help during your time at university.

If the research is thorough, can most obstacles be overcome?

There are a small number of courses that may not be suitable for some disabled students. However, on the whole it is usually possible to overcome most difficulties. The most important thing to do is make contact with the disability adviser at your chosen university as early as possible; at MMU we start working with disabled students around Easter time in preparation for starting a course in September.

If you want to get a step ahead, it is worth finding out who your local education authority is and requesting a 'DSA1' form (to apply for Disabled Students Allowances) as early as possible, you will also need to get 'medical evidence' which can be a letter from your GP. The letter needs to say: the name of your disability or health condition; when it was diagnosed and how long it is likely to last; the main difficulties that you experience i.e. mobility impairment or concentration difficulties; any side effects of medication that you are taking (e.g. fatigue); and how your study is affected.

Your medical evidence does not need to say what support you will need as this is the part that your disability adviser will assess you for. If you have any other difficulties such as dyslexia or depression, please speak to your disability adviser to make sure that these are also taken into consideration.

Do most colleges and universities have a disability adviser on site?

Most universities and colleges have a disability adviser on site but the number of advisers and name of the service can vary from place to place, for example, at MMU we have the Learning Support Service which is open every day (including holidays) but a smaller college may just have one person who works part time and it may be called the Disability or Dyslexia Service rather than Learning Support.

What are the problems disabled students may face when they have started their course?

You will have an assessment (hopefully before the start of your course) which will look at the difficulties you are likely to encounter during your course (e.g. taking notes or moving around the campus) but it is sometimes difficult to anticipate all of your long-term needs at the first assessment. Once you have settled into your course, you may find that you need to contact the disability officer at your university/college again, to look at things that you weren't aware of before you started.

Anna Charles-Jones

Is much help available?

Most disabled students on university degree courses can apply for Disabled Students Allowances (DSA) which is money that comes from your local education authority. DSA can be used to pay for any support that you may need whilst studying such as study skills tutors, mobility assistants, dictaphones and computers etc DSA does not cover any personal care which you may need; if you need personal care support, this is usually your responsibility to arrange, through your home social services department before you move to university.

Do students with a disability find it harder to settle in and get involved in activities and new social groups, or does that really depend on their personality?

How you settle in at university will vary from person to person, some people find it easier to make friends and everyone can find themselves feeling a little homesick regardless of whether they are a disabled person or not. It is important to remember that when you start at university, you won't be the only one who doesn't know anyone!

If you choose to live in Halls in the first year, you will be surrounded by other students who have also just moved away from home and you are likely to find friends very quickly; another good way of meeting people is to head down to the students' union who usually put on 'freshers' fairs' in the first week of term; you can sign up to join different clubs and societies and meet different people this way and there's always the other people on your course too.

ASBAH's publication: Leaving home for University or College is full of information and tips for students, you can order it online at ***www.asbah.org*** or via the helpline on **0845 450 7755.**

Looking at the bigger picture

ASBAH education adviser, Naomi Marston, recommends a new resource pack from the Transition Pathway charity which provides a host of relevant information to support transition planning with young disabled people aged 13 – 25.

The Transition Pathway pack includes Transition Pathway guidance and tools for person-centred transition planning, a book, and an interactive CD. Also in the pack is a book called The Big Picture, aimed at young people, which is clearly laid out with simple language and lots of visual aids.

Naomi said: "There is plenty of information and guidance about transition using a person-centred approach, to help young people plan their future."

The pack can be used by anybody who is involved in supporting a young person in transition to adult life such as parents, carers, teachers and social workers.

The Transition Pathway resource pack costs £45 (plus £5 p&p). The additional Big Picture book costs £5 (plus £1 p&p)

To find out more visit ***www.transitionpathway.co.uk*** or email Chris Sholl at transitionpathwaypartnership@yahoo.co.uk

Alternatively call **07947 917554** for more information.

KEY POINT

- Anna Charles-Jones discusses going to university
- Continence adviser Gill Yaz gives some practical tips for parents and teenagers

Continence through the transition years

Continence adviser Gill Yaz gives some practical advice for parents and teenagers

Personal continence management is an area that parents and carers should address as early as possible, believes ASBAH's continence adviser Gill Yaz.

Encouraging young children to become involved from an early age makes personal continence care a part of their life so they become used to the idea of taking complete control in their teen years.

"It's important not to expect a teenager to suddenly take complete responsibility," Gill said. "If possible don't leave it until the transition years because it is much harder for a young person because they don't feel ownership.

"It's very easy to fall into the trap of saying, you should be doing this for yourself by now, but that just creates another area of conflict.

"The teenage years are difficult enough because there is already so much to contend with, working out who you are and where you fit in.

"If you have a disability then you have additional things to think about and come to terms with. Many of the teenagers I've worked with feel that everyone is suddenly piling responsibilities on to their shoulders."

Parents and carers should feel free to approach professionals including ASBAH advisers, GPs, paediatricians and urologists, for information and advice on continence issues and sex, an area which Gill says has been neglected until recently.

But she added that teenagers won't cooperate unless they want to, and parents and carers simply have to accept that they aren't ready for that message at that time.

She said: "We can talk for hours about the importance of cleanliness and self catheterising regularly to prevent kidney infections which can lead to kidney failure but sometimes the young person won't take it on board. Teenagers rarely have any sense of their own mortality. Nagging often makes things feel worse for everybody, and doesn't really work. Getting different people to repeat the 'nag' message also doesn't work!

"It's often useful to ask the young person what the problems are. The usual comments are that it is time-consuming, boring and prevents them from doing what they'd rather be doing, be that watching TV or hanging out with their friends, particularly during school breaks and lunch hours.

"Acknowledging that you understand can help. Sometimes making practical changes to the routine can speed up the process, making it less of a chore.

Sometimes they may be using inappropriate equipment and asking the Continence Nurse if the catheter size is still correct, for example, can help."

When you do have appointments with healthcare professionals plan out what questions you'd like them to answer beforehand.

And you need to be honest about what you want and what you are prepared to do yourself. That way everyone can work to accommodate the young person's needs.

Below the belt

You'll find plenty of practical help and information on how to survive the difficult teenage years in ASBAH's *Below the Belt*.

The 32-page booklet deals with everything from spots and raging hormones to pressure sores, continence issues and parents who just won't let go...

The booklet costs £5 plus p&p for UK individuals or £10 plus p&p for professionals and non UK orders.

Obtain your copy through the website www.asbah.org or by calling the Helpline on **0845 450 7755.**

Medical Care

Some people with hydrocephalus make a smooth transition to adulthood without needing additional support and advice from ASBAH.

Here area adviser Angela Lansley outlines the ideal care package which ASBAH believes should be on offer to young people with hydrocephalus. Unfortunately, the quality of health care on offer does vary quite widely from area to area but knowing what the ideal looks like will help parents and young people to press for the best service possible

Angela said: "At ASBAH we believe that the ideal scenario should be offered to all our service users and indeed many people are very happy with the quality of care they receive.

"However our team of advisers usually hears from people who are experiencing problems and this does tend to colour our views.

"Readers may be concerned when they read 'The Reality' section. While I certainly don't want to alarm anyone, I think it is always useful to know what problems could arise."

The Ideal

Health Care Plan: this should be drawn up during school years, perhaps as part of person-centred planning.

Gradual preparation for the change to adult care: to help young people take on the responsibility of dealing with their own health care. It also gives the chance to learn to communicate with health professionals without the support of parents or a carer.

Protocol for adult care: what medical care you should expect as an adult and when: for example, shunt monitoring, checking renal function.

Transition health workers: these are in post in some areas. In Liverpool, for example, we had a multi-disciplinary health care team who would, when possible, attend a school review before a young person transferred to adult care. This team no longer exists but one of the PCT's case managers has been designated to deal particularly with transition and it will be interesting to see how this works out.

Clear pathway to provision: hydrocephalus care pathways operate in some areas such as Leeds and Cornwall and these lay out clear guidance for patients and professionals on accessing specialist care.

Knowledgeable staff / accessible and readable information: staff in adult medical care need to be aware of the difficulties some people with spina bifida / hydrocephalus have in taking in and remembering information. Staff at our local Walton Centre for Neurology and Neurosurgery are picking this up as an important area and are also aware of the shock to the system for young people moving from the familiarity and homeliness of the children's hospital to the impersonality of the adult sector.

The Reality

Alas, we don't live in a perfect world and in reality the health care during this transitional stage is very varied. Some areas, particularly in the South East, offer excellent holistic clinics where all medical needs can be met under one roof. In other areas you may need to travel to different hospitals, which can be stressful and time consuming.

Coping with adult hospital environments: if you have enjoyed good paediatric care, moving into the adult hospital environment is often a shock. If you are disabled, you may find your care needs may not be well met – especially in continence management - and carers may not be catered for.

Local district general hospitals: these may have poor levels of knowledge of the condition/s or management techniques, for example they may delay seeking specialist advice on potential shunt problems or be unable to deal with people who have an ACE for bowel management, or who need intermittent catheterisation.

Uncertainty about the time of transfer to adult care: depending on the consultant, differing age limits etc. You may be transferred from one consultant for part of your care and stay in the paediatric sector for another.

Split care: You may have to use three different hospitals e.g. for neurosurgery, orthopaedic and urology care. This can be stressful, time consuming and de-personalising.

Community health services: are often difficult to access. There may be long waiting lists, complicated referral systems or lots of staff changes to cope with.

New guide offers transition advice

The Department for Children, Schools and Families has launched a new guide to help with the transition from secondary to further education.

The guide, available online, covers ages 14 to 19, with information on everything from Year 9 options to coursework and exams. Other sections offer advice on options after 16+ whether the student opts for sixth form, college or work.

There is also a link to a section for disabled people, with details about drawing up a Transition Plan which outlines what you as a disabled young person want to achieve in the next few years. It includes the support you will need to live as independently as possible and every aspect of life, including education, employment, housing, health, transport and leisure activities.

For details of the 14 to 19 – Your life, your options information, go to: ***www.direct.gov.uk/en/EducationAndLearning/14To19/***
For information about Transition Plans go to: ***www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/Schools***

Advice from the experts

***Link* talked to ASBAH's Naomi Marston, an education and employment adviser based in the south east, about the importance of accessing as much support and guidance as possible to make the path through the transition years of 14 – 19 as smooth as possible.**

"Transition Plans are statutory for children with a disability. There may be variants from area to area, but the format is generally the same wherever you are in the country.

"There is a lot of information and help available to help young people achieve the most, but it is important that they consider all aspects and don't rush into anything.

"For many people leaving home at 18 is much too early, even though they may feel ready. Sometimes signing up for a life skills course at a local college is more appropriate than going away to university straight away. Or look at specialist colleges such as the National Star College in Cheltenham, where students study and learn life skills at the same time.

"Moving away from home is a huge step for anyone, particularly for those with a physical or learning disability, so it is important that they are fully capable of caring for themselves. My advice would be to take things one step at a time.

"Many of the people I work with have hydrocephalus and one of the areas we work on is creating a personal profile, to find what they are good at and what they enjoy doing. Often they have a different perception of their abilities which can lead to inappropriate career choices.

"If teenagers are clashing with their parents about what they would like to do it can be helpful to involve professionals such as teachers, social workers and career advisers. Organising a meeting on a professional basis can be more effective and keep discussions on a calmer footing.

"There's no doubt that Transition is a huge area as it involves education and employment changes. But with plenty of research and planning there's no reason why young people can't move forward in a positive way."

Naomi is currently working with other ASBAH advisers to put together a comprehensive Transition Pack. This will offer useful information, ideas and suggestions for young people, their parents as well as employers.

Watch future issues of *Link* for the launch of the new pack.

> **"I think it was important for me to go to mainstream school and college but I found my teenage years quite difficult because I felt different to everyone else. I had a small group of close school friends but it was very important to meet up with other young disabled people outside of school."**
>
> ***ASBAH service user***

Career Advice

Connections Direct provides advice on learning, careers and more. If you are disabled or have a learning difficulty, you can get support up to the age of 25.

www.connexions-direct.com

Freephone **0808 001 3219**

Employment support

If you need extra employment support because of a disability, your local Jobcentre Plus office can put you in touch with one of their Disability Employment Advisers.

Disability Employment Advisers (DEAs) can give you help and support regardless of your situation. They can help you find work or gain new skills even if you have been out of work for a long time, or if you have little or no work experience.

www.direct.gov.uk/en/DisabledPeople/Employmentsupport/LookingForWork

Putting people in control

The Government plans to transform Social Care over the next three years through the introduction of Personal Care budgets' to put people who receive funded care in control of their support.

In December, Health Secretary Alan Johnson announced that an extra £520 million of ring fenced funding will be allocated to councils as a Social Care Reform grant over the next three years.

The grant includes some NHS resources, in recognition of the impact social care can have on improving people's health and well-being.

One key element of the programme is giving the majority of people who receive funded care their own personal budgets so they can choose the support services they want for themselves or a family member.

Initiatives such as first-stop shops will become common place so that everyone, including people who don't have support from social services, will have access to advice and advocacy about community services, such as local community equipment providers or domiciliary support and transport *link*s.

There will also be closer collaboration between the NHS and local government so that people receive more coordinated and efficient support in the community.

A government spokesperson said: "Support for individuals and families when they need it is of vital importance to all of us.

"These proposals for personal budgets will allow all those who would benefit from a personal budget to receive one, putting real control into the hands of those in care and their carers, leading to far more personal and responsive care."

For more information about personalised budgets visit ***www.in-control.org.uk***

Transition – Social Issues

Today the majority of parents, carers and professionals are aware of the emotional and social issues associated with being disabled in society.

This awareness becomes increasingly important as the child matures through adolescence and moves into adulthood.

This transition phase can be particularly difficult for an adolescent who is dependent on others for physical care and other independent living skills.

The young people who plan to leave home face many other issues associated with independence, such as budgeting, transport, suitable housing, benefits and others.

It isn't an easy phase, but then the teenage years rarely are. Try and plan ahead as much as possible and don't be shy of asking the relevant agencies for whatever help and advice you need.

Teenagers and young adults with a disability should be given help as early as possible in independence skills.

Other issues that should be addressed early on are education choices, alternatives to work, and social activities.

Social isolation can be a problem for a lot of college students who don't have out-of-college contact with their peer group and depend on their families for social contacts.

Sometimes these difficulties have their roots in the condition (e.g. some people with hydrocephalus who find relationships difficult).

Problems can also arise when the young adult doesn't share common experiences with their peers because they perhaps have separate transport to college or work, or aren't able to hang around and do things on the spur of the moment.

Some advice for young people on what the ideal preparation for adulthood should include:

Person-centred planning / reviews: from year 9 onward – this means finding out what you really want and drawing up a plan to see how it can be put in place for you.

Good personal, social and health education (PSHE) and relationships counselling taking account of your disability.

Self-advocacy and assertiveness training: helping you to say what you want to say in the most effective way.

Good benefits advice: not just written information but someone to explain the system and to tell you how claiming your own benefits might affect your family too.

Choice: about where you want to study. Maybe you would like to go to a college outside your local area or to a specialist residential Further Education college.

Transport: to support that choice and transport training if you have a learning disability or lack confidence in using public transport.

Good support in higher education: maybe help to find a disabled-friendly university, to check out your benefits and to apply for Disabled Students Allowance to fund any extra support or equipment you might need at university.

Access to mainstream educational and social facilities and the confidence to use them.

Easy access to adult social care services: whether you choose to use services provided by your local council, a private agency or to make your own arrangements through direct payments or personalised budgets.

Accessible housing or supported living: if you want to move away from the family home.

Access to good advocacy services: if you need help in putting your needs and wishes across to others.

Careers and Employment advice: accessible, disability-sensitive and continuing, if you need it, until you are 25.

But it isn't always so easy…

Planning: person-centred school reviews do not happen everywhere and person-centred planning is often available only for people with learning disabilities or needing a lot of support.

Further Education: while some colleges are excellent and give disabled students the support they need, others have a long way to go. Recently we have come across students on incapacity benefit having to pay something towards college fees which were previously free.

Transport: Some councils provide transport to college from 16-19 but others stop at 16. Some want a financial contribution. Everyone is keen for disabled people to use mainstream services in education or leisure instead of specialist ones but it does mean that people usually have to make their own transport arrangements.

Social Services: it is getting harder to get support from adult services as it is often restricted to those in very great need. Some people struggle to find support workers to employ under the direct payments system and the new personalised budget services are only just getting going in most areas.

People often complain that it is hard to contact adult services or to get social work support; sometimes professionals promise to ring them and don't.

Housing options: there is a shortage of accessible housing or housing with extra support. Students who have come home from residential college and other young adults wanting to look at alternatives to remaining in the family home can be disappointed.

Careers and employment advice: some areas are well-served with good Connexions advice and specialist employment schemes for those who need them but services are very variable and it is often hard to get good support if you have been out of school or college for a while or good advice about the impact of work on benefits for you and the whole family.

Benefits: Some Jobcentre Plus staff have been poorly informed about benefits for disabled young people. The system is due to change this autumn with the introduction of the Employment Support Allowance.

Help: if you do come across any of these problems and difficulties there is lots of information and advice available on how to get the best you can from services involved in transition. Look at the Online help section of this supplement, speak to your ASBAH adviser or phone the ASBAH helpline on **0845 450 7755.**

Case study

***Link* talked to 21 year old Jennifer* from the North West who has hydrocephalus and Cranium Bifida (a failure of the development of the bones in the skull) about her experiences of transition.**

"I found the transition time very tough. Being 17 was particularly horrendous, although that was mostly because I was very ill.

"I have two shunts for my hydrocephalus and Dandy Walker cyst, and I experience bad headaches because of the surgery.

"In 2003, unbeknown to me, my catheter disintegrated and after a day of particularly bad headaches I collapsed. I went blind and was paralysed in all four limbs. Both these ailments were thankfully only temporary but for a terrifying few hours I feared they were permanent. I underwent emergency surgery to have new shunt tubing inserted into my body

> **I was transferred rather suddenly from paediatric to adult services. I found this very daunting because it became all about me making decisions.**

"Two years later, I underwent an emergency operation when my shunt disconnected. I experienced temporary paralysis for the second time.

"I was transferred rather suddenly from paediatric to adult services. I found this very daunting because it became all about me making decisions. My Mum was allowed in consultations with me and I did look to her for a lot of support at the time.

"More recently I have gained in confidence and have felt more capable of making decisions on my own, but it has been a gradual process. I think it is important to take things gradually. I still experience anxiety when I try to make decisions on my own.

"I attended a special school until the age of 19, moving in to the Post 16 unit after sitting a single GCSE at a local mainstream high school.

"We were taught life skills in the Post 16 unit such as basic cooking and shopping to help our independence, but I did miss quite a large chunk because I was ill. However I was provided with an opportunity to develop culinary skills through weekly occupational therapy sessions at school.

"After school I went to college to start a Performing Arts course. The college was supportive in that it allowed me to take what is usually a one-year course over two, but I found I couldn't manage and dropped out after a few months. I was unable to manage because of discrepancies about work I was doing at home.

"My motor skills aren't great and I'm not a quick writer. I find culinary skills difficult and need assistance with this. I also have poor short term memory which means some people who don't fully understand the condition think I have low intelligence.

"I recently re-sat the GCSE at a local college with more success than the previous course. I am continuing my singing lessons, focusing on Italian Opera. I'm also involved with a local group which I love. Singing gives me so much pleasure and somehow I don't find it difficult to learn and remember the lyrics.

"I am becoming more independent but still need a carer for eight hours a week to accompany me when I go out. I have been able to access the Direct Payment Scheme via social services. I need someone with me who knows what to do in an emergency because when I have a shunt problem, I deteriorate extremely quickly and can be fighting for my life within a very short time.

"At the ages of 15 and 16 I was rather a loner and spent a lot of time at home in my bedroom. It took another couple of years before I was confident enough to go out with help.

"These days I do have a good circle of friends although they don't live locally so I am always dependent on someone to take me to meet up with them.

"I try to live with head pain which varies in its severity. I suppose I could feel very bitter and resentful that my hydrocephalus puts restraints on my life.

"But feeling like that doesn't help anyone so I do my best not to let it get me down. There are always people worse than you."

** Name has been changed to protect identity.*

Online help

There's a wealth of information about transition on the internet. Here are some of the many websites which are worth looking at:

AFTER 16: Information about opportunities and services after school, benefits, transport, employment, friends, health and more. ***www.after16.org.uk*** This will take you to the Transition Information Network or you can use ***www.transitioninfonetwork.org.uk***

CONNEXIONS SERVICE: A national support service for all young people aged 13 - 19 to help to prepare them for adult life. Connexions can support people with learning difficulties and disabilities until they are 25. ***www.connexions.gov.uk***

CONTACT A FAMILY: A UK-wide charity which provides support, advice and information for families with disabled children, including information on transition. ***www.cafamily.org.uk***

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COUNCIL FOR DISABLED CHILDREN: Information on a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs, including information on Transition.
www.ncb.org.uk/cdc

DEPARTMENT FOR CHILDREN SCHOOLS AND FAMILIES: If you go on the home page and click on Young People then on Young Disabled People, you can access information on further and higher education. The Higher Education section gives information on Disabled Student Allowances and Extra Financial Help.
www.dfes.gov.uk

DEPARTMENT OF HEALTH: The website has information about strategy, policy, guidance, publications and more. To get to the information on Transition go to www.dh.gov.uk and put 'transition' in the search box – result 4 of the search is the section on Transition from children's to adult services.
www.dh.gov.uk

DISABILITY RIGHTS now comes under the Human Rights Commission and on their website they give advice and information to disabled people, employers and service providers. They also support disabled people in getting their rights under the Disability Discrimination Act.
www.equalityhumanrights.com

MOVING ON UP: A website for young disabled people from minority ethnic communities.
www.movingonup.info

NATIONAL CENTRE FOR INDEPENDENT LIVING: Advice on independent living, direct payments and personal assistants.
www.ncil.org.uk

SKILL: A national charity that promotes opportunities for young people and adults with any kind of disability in post-16 education, training and employment in the UK.
www.skill.org.uk

0845 450 7755

Helpline celebrates its second birthday

In two short years ASBAH's Helpline and Information Service has established itself as the first point of contact for service users.

Since its launch on 1 June 2006 the helpline team has handled thousands of enquiries, providing support on all aspects of spina bifida and hydrocephalus to parents, carers, individuals and professionals.

If the helpline manager, Linda Lewis and operators Annie Kilsby and Dawn Stilwell, can't answer the questions themselves, they provide access to medical and educational advisers or support at a local level.

Linda Lewis

"We receive a real mix of enquiries," said Helpline Manager Linda Lewis, "from parents and family members to health professionals and outside agencies calling on behalf of their clients. Most people contact us by telephone but the number of emails has doubled since last year, probably because emails are a convenient alternative to using the telephone especially when the helpline is busy or the office is closed".

> **It is always lovely to receive people's feedback on our service and learn how we helped to make a difference to someone's life.**

"We have a lot of people phoning back or writing in to say thank you. It is always lovely to receive people's feedback on our service and learn how we helped to make a difference to someone's life."

The helpline is currently working on promoting the service by sending out information and flyers to hospitals and libraries.

Linda said: "It's important to keep ASBAH fresh in the minds of everyone in the spina bifida and hydrocephalus community. We have learned from our callers that some people have either forgotten or do not realise we are here to provide support at all stages of their lives, not just the times when they are faced with a crisis.

"No matter how small the query may appear the helpline is there to provide answers to your typical daily living issues, such as finding suitable travel insurance or looking for particular clothing or equipment that is not usually available on the high street.

"It's also important to remember the helpline can provide callers with access to a range of other services provided by ASBAH.

"We can arrange contact with regional advisers in most parts of the country. This is an important service providing support and information at a local level. It is particularly helpful when callers require assistance in completing their benefits forms or are looking for local social groups and events.

"Other sources of support and information can be provided by our specialist advisers who can assist you with your medical and educational enquiries."

KEY POINT

- **Helpline celebrates second year of operation**
- **Access to a wide range of services through the Helpline**

Helping… young adults

A young man who has spina bifida and is a wheelchair user called to ask for the best way of getting across London using the public transport system. He was keen to make the arrangements himself to prove his independence to his mum. The helpline directed him to suitable websites which would give him the information he needed.

Helping… midwives and GPs

The helpline receives many queries from midwives and GPs who want to check up on the latest information about folic acid dosages or to request more information about ASBAH's campaign to fortify UK flour with folic acid.

Helping… with NPH

One lady called in because she was worried about her husband who had been diagnosed with Normal Pressure Hydrocephalus (NPH). She was sent information leaflets and a copy of ASBAH's NPH CD Rom to help answer some of her many questions.

Helping… students

One young lady who is a student nurse sent in a £5 donation to say thank you for the literature about spina bifida and hydrocephalus which the helpline had sent out to her. The staff really appreciated her thoughtful gesture.

ASBAH believes it is important to provide support to students to capture their interest in these disabilities.

Helping… care home staff

A newly appointed manager of a nursing home called and asked for information leaflets about spina bifida because one of her residents had the condition. Helpline staff were thrilled that she had taken the initiative to find out more so her team could provide a good level of care.

Helping… adults

Calls from adults who have been told they have spina bifida occulta are not uncommon. Linda said "We recently received a call from a man in his 40s, who had been involved in a car accident. An x-ray revealed that, unknown to him, he had spina bifida occulta. Of course he was very surprised to hear this and was keen to find out more. We were able to send him information in the post and put him in touch with a specialist adviser."

Helping… education professionals

A teacher called in for advice about what sporting activities a child who has a shunt can safely get involved in and the team were able to provide her with the latest guidelines to enable her pupil to get the most out of school life.

Helping… parents

One anxious parent called in because they were worried their child may have a blocked shunt as she was lethargic and vomiting. The parent was connected to a specialist adviser to discuss the symptoms further and was told to take the child to hospital straight away. Several days later the parent rang back to let ASBAH know that within an hour of being at the hospital, her daughter underwent a successful emergency shunt operation.

Helping… with BIH

People with benign intracranial hypertension often call in for advice on managing headaches. For some people alternative therapies such as reflexology and Indian head massage help to reduce symptoms and we can direct people to where they can find out more. But staff always point out that every case is individual and they should check with their healthcare professional before proceeding.

Fact:

80% of queries are dealt with on the spot by the helpline team.

20% of queries are passed on to ASBAH's medical or education and regional offices, or the person is referred to another organisation that can help.

Helping… grandparents

The helpline received a call from a lady who was concerned about her pregnant daughter who was carrying a baby with spina bifida. Staff could provide her with plenty of relevant information.

How people contact the helpline:

55% by telephone

33 % by email

12 % by letter

Codman - Working in partnership with ASBAH

Living with a child with hydrocephalus

A new study by children's nurse Joanna Smith has focussed on understanding parents' experiences of living with a child with hydrocephalus.

Joanna told *Link*: "My interest in hydrocephalus developed from caring for children with hydrocephalus and their families when working as a nurse on children's neurosciences ward.

"This interest initially related to ensuring parents had the skills to recognise signs of shunt malfunction when discharged from hospital. However, over time I realised the child and family's lives were being disrupted because of the potential for shunt malfunction, but there was little information about parents' experiences."

She added: "In some ways the findings confirmed areas that we already knew about in relation to parents living with children with other long-term conditions, such as parents 'getting on and living a normal life'.

"However, the amount of uncertainty parents described not only in relation to shunt malfunction but also the child's future were more surprising."

Here Joanna writes about why she chose this subject and discusses her findings.

What prompted the study?

Several factors prompted this study, including an awareness that:

- Parents of children with shunted hydrocephalus need to develop the skills necessary to recognise acute changes in their child to detect shunt malfunction
- Children with shunts often have many admissions to hospitals because there may be a problem with the shunt
- Parents know that hospital admission is disruptive for the child and family, and it is likely that child will have to undergo a CT scan to assess the shunt; on the other hand parents know that if the shunt is not working properly the child could become seriously ill and require urgent surgery.

The findings of this study have the potential to improve services to help parents decide where and when to seek support when they are worried that their child's shunt may be blocked.

Who took part in the study?

Twenty-five parents, a mix of mothers and fathers, participated in the interviews.

What did we learn?

Talking to parents was very valuable and provided much information about what it is like to live with a child with hydrocephalus. Three key areas were identified from the information parents provided:

Uncertainty

Parents described their concerns about how hydrocephalus would affect their child when they were first told about the condition. They felt unsure about their child's future. Parents felt they were constantly looking out for the signs of shunt blockage because it could occur at any time.

Ben's mum described what it is like living with Ben when his shunt could 'block' at any time:

"It's there, it's there – hydrocephalus - all the time and you worry and are stressed out about it. The biggest worry is if the shunt blocks... you constantly ring the hospital and take him to the doctors to be checked. So that really is - how it is."

Recognising and responding to changes in the child's condition

Parents gain a great deal of expertise in being able to distinguish between general childhood illness and shunt malfunction in their child. Parents felt their expertise was not always recognised by healthcare professionals. In addition, they felt services for the child and family lacked co-ordination.

Abbey's mum described how she distinguishes between the subtle differences when her daughter has a 'flu bug' compared to a 'shunt problem':

"My daughter had this flu bug, that has been going round, about a fortnight ago with the high temperature, blinding headache, nausea, which for her are normal shunt problems but I just know there are subtle differences. And also her sister had had it the previous week which reassures me and is my benchmark."

Living a normal life

Most parents said they just get on with everyday life but that there were times, particularly when their child was ill, that the possibility of the shunt blocking dominated day-to-day family life.

Jason's dad described how they participated in things others families did but that it needed to be planned ahead:

"Don't stop going on holiday, even abroad. You can find out about hospitals that do know something about hydrocephalus before you go. Just go on the internet and check the hospital in Spain does that and there is no reason why you can't travel."

What did parents suggest?

Parents made several suggestions about how to make services better:

- Have a key named worker for children with hydrocephalus
- Have more joint out-patient clinics
- Listen to parents, they know their child best.

What will happen next?

The full results of the study will be written up as a thesis by Joanna Smith as part of a PhD. A summary of the study has been presented at local ward seminars and relevant parents groups. The findings will also be published in healthcare journals and presented at national/international conferences.

Building on these findings, a second study is being carried out to explore how parents and healthcare professionals come to a decision, when a child is admitted to hospital with suspected shunt malfunction.

The study team would like to express gratitude and thanks to all of the parents who took the time to participate in this study and shared their experiences.

For further information about this study please contact:

Joanna Smith, School of Healthcare
Baines Wing
University of Leeds
PO Box 214
Leeds, LS2 9UT
e-mail: *hcsjsm@leeds.ac.uk*

Catching up with **Aqueela**

Long-time *Link* readers may recall the story about little Aqueela Essopjee whose plight touched the hearts of Codman staff.

Aqueela Essopjee, who was born in Lusaka, Zambia, on 18 May 2003, was diagnosed with hydrocephalus when she was six weeks old.

Her parents, Sadick and Nazarene Essopjee, were relieved when Aqueela had her first shunt inserted just two days later. When this failed, a second one was fitted at the beginning of August. But this also blocked and her condition began to deteriorate.

Her family, including extended family in England, was very concerned about Aqueela.

Her great aunt, Kay Butt, who lives near Watford with husband Dean, began to search for a solution - to locate a shunt that would work.

When they contacted ASBAH, Senior Medical Adviser, Rosemary Batchelor, put the couple in touch with Graeme Loughlin, Codman's UK Country Manager at that time.

Graeme told Kay and Dean that he could possibly supply a suitable shunt valve with an antibacterial impregnated catheter system, known as the BACTISEAL ™ shunt, to try to combat the high risk of infection.

Dean said: "Graeme arranged for two shunts - one back-up - to be flown to Lusaka from the UK on behalf of Codman.

"At the same time, Aqueela had had two seizures but the shunt arrived, after some hair raising moments, two days after these, on 25 September.

"She was operated on that night and was already better the next day. She was out of hospital within a week. We will never ever forget Graeme's kindness."

Today Aqueela, who celebrated her fifth birthday in May, is thriving. She started nursery in March 2007 and happily interacts with the other children.

Aqueela speaks English and has also learnt three other languages that are spoken in the homes of her family members, namely Gujarati, Urdu and Nyanja.

Her mother, Nazarene, explained: Aqueela has learnt Gujarati in her home environment with my husband and I. The Urdu language is spoken amongst my sister-in-law and her children, Aqueela's cousins, who are from Pakistan originally.

"Nyanja, which is the local African language in our area, is spoken by Aqueela's carer, who has been with us since she was born.

"As she understands all these languages well, we have to be mindful of the topics of conversation we can have within her earshot. She is very attentive, alert and aware as to what is happening around her."

This year Aqueela is in her second year of nursery. She wears a uniform to school and is accompanied by her carer, because she has been getting silent fits.

Nazarene added: "She loves playing doctors and that's what she wants to be when she grows up. We have brought her a doctor's set and she loves taking any willing person's blood pressure and temperature."

It is wonderful and extremely rewarding to hear about Aqueela's amazing long term progress. Stories like this reinforce how critical it is to have the support and reach of organisations like ASBAH.

Together we hope to builder stronger awareness and better access to the best therapies for treating and managing hydrocephalus and its associated complications.

**Graeme Loughlin,
EMEA Product Director,
Hydrocephalus
Codman**

KEY POINT

- Aqueela helped by Codman mercy mission
- Aqueela now in her second year of nursery

Breaking new boundaries

ASBAH is set to benefit by £5 for every visitor to the Beyond Boundaries Live exhibition who registers online for free show tickets, using ASBAH's code number.

The event, now into its second year, will be held at the Kent Showground near Maidstone on 25 and 26 July.

It promises to be a highly interactive exhibition showcasing a large assortment of products and services within the disability sector.

Beyond Boundaries Live will focus on everything from holidays, employment, sports, the arts, fashion, vehicles, children's activities through to the latest services and development from professional bodies such as The College of Occupational Therapists.

Leading exhibitors from within the disability industry will be present.

Visitors will also be able to join in special activities ranging from dance and drama workshops, football, basketball, new age curling and wheelchair skills training.

Beyond Boundaries Live is all about making all aspects of life, be it sport, fashion or just cooking easy and accessible

The outside area will feature activities such as rock climbing, adaptive rowing, cricket, shooting, falconry and even a test driving track to test drive the latest cars, handcycles and wheelchairs.

Sales Manager Christie O'Conner told *Link*: "Beyond Boundaries Live is all about making all aspects of life, be it sport, fashion or just cooking easy and accessible."

Visitors will also be able to hear several speakers including Olympian Ade Adepitan, X factor finalist Kerry McGregor and 11 times Paralympics gold medallist Dame Tanni Grey-Thompson, in the two seminar theatres.

To register for your free tickets or get more information please visit *www.beyondboundarieslive.co.uk* or call 0208 971 8286.

In order for ASBAH to receive £5 per visitor who registers online, please use ASBAH's code number AC005. You must also present your ticket at the show. Tickets are free.

Thanks for the funding

Comic Relief's funding of the Your Voice Policy Officer for the past three years has given a new lease of life to ASBAH's adult user group.

Having a part-time member of staff, Barbara Robinson, dedicated to Your Voice work has taken much of the time-consuming organisational and admin work away from the committee.

The committee members, all volunteers, have valued Barbara's support which has enabled the group to organise more events. Her role includes dealing with the many Your Voice queries as well as monitoring the website and co-ordinating the newsletter.

The funding came from Comic Relief's Fighting for Justice programme which helps groups such as Your Voice to make sure their needs are met and supports their push for change.

With Barbara's help, Your Voice has arranged a host of successful events including 'Be a Sport for Leisure or Pleasure', 'To Work or not to Work', 'Ageing Disgracefully', 'Moving On Up' and the Hydrocephalus Information Days.

The group is currently looking forward to the two events planned for 2008 – 'Looking Good, Feeling Great' at Worsley Park, Manchester on 11 – 13 July (which is already fully booked) and the 'Have Wheels Will Travel' mobility weekend at the Leicester Marriott on 31 Oct - 2 Nov.

The Your Voice website, launched in February, another initiative made possible by Barbara's appointment, now boasts an impressive 104 registered users, with more signing up each week.

Your Voice committee member Lisa Cain told *Link*: "Thanks to Comic Relief, Your Voice has been able to set up its own website and also produce a twice yearly newsletter. We have been able to hold more events on different subjects in a variety of locations to benefit our membership. All this has enabled our growing number of members to become more proactive in their everyday lives."

YOUR VOICE STATS

404 members

104 online members

Your Voice presents

Open to all adults (aged 18 and over)

Have Wheels Will Travel

Date and venue:

Friday 31st October to Sunday 2nd November 2008

Leicester Marriott

Book NOW

Weekend delegate rate £95 includes accommodation, workshops and meals.

Day delegate rate £30 (Saturday 1st only) includes workshops and lunch.

The delegate rate is being subsidised by Your Voice

Presentations:

More speakers to be confirmed

Maggie Pickard of Extend will present a session on how to maintain and improve mobility.

Geoff Wright will speak about his his exploits travelling around Britain: from Lands End to John o"Groats by scooter.

Paul Manning will talk about journey planning for train and coach travel.

Wendy Coley from Dogs for the Disabled will speak about how dogs can be trained to help people with disabilites.

There will also be information available for people to take away on:

- Mobilise (formerly the Disabled Drivers Association)
- The British Disabled Flying Association
- National Association of Bikers with Disabilities
- Information about Driving Assessment Centres

For further information and to register your interest contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbarar@asbah.org
Telephone: 01733 421322

association for spina bifida hydrocephalus
ability beyond disability

Registered charity no.249338

Coloplast

sia
spinal injuries association

association for
spina bifida
hydrocephalus
ability beyond disability

Bowel Management Roadshow 2008

Coloplast Ltd in conjunction with SIA and ASBAH are pleased to present a series of bowel management open days

Call in and find out about the latest Bowel Management solutions including the **Peristeen Anal Irrigation System** and have the chance to speak to a local spinal nurse or continence advisor.

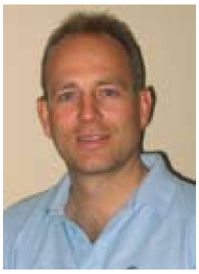
- SIA & ASBAH in attendance
- Product Demonstration Area
- Refreshments provided

Roadshow Events for 2008

7th July	–	Hilton **Cardiff**, Kingsway, CF10 3HH
8th July	–	Best Western Leyland Hotel, Leyland Way, Leyland, **Preston** PR25 4JX
9th July	–	Best Western Valley Hotel, Buildwas Road, Ironbridge, **Telford** TF8 7DW
10th July	–	Holiday Inn **Sheffield**, Royal Victoria Station Road, S4 7YE
24th July	–	Holiday Inn **Gloucester**, Crest Way, Barnwood, GL4 3RX
25th July	–	Holiday Inn **Bexley**, Black Prince Interchange, Southwold Rd, DA5 1ND
31st July	–	Ramside Hall Hotel, Carrville, **Durham** DH1 1TD
1st August	–	Holiday Inn **Aylesbury**, Aston Clinton Road, HP22 5AA

Guest Appearance

Come and meet sporting personality **Michael Cogswell**, who will be on hand to share his experiences.



Michael Cogswell
Sailing Team GBR 2003 - 2007

*"As a paraplegic and sports-person competing internationally, **Peristeen** Anal Irrigation gives me the total security and reliability I need to travel, train, and race without bowel problems."*

Open 12 to 5pm – call in anytime for coffee and a chat

To register your free place, please call **Cindi Brooks** on **01733 392 061** or email **gblbr@coloplast.com** – or drop in on the day!

Peristeen

Coloplast

Coloplast - Working in partnership with ASBAH

Children's bowel management booklets

ASBAH and Coloplast have teamed up to launch two new booklets to give children and teenagers more information about a new method of bowel management.

The 12-page booklets, which will be available this summer, explain how the Peristeen Anal Irrigation system works in easy-to-understand language.

Peristeen Anal Irrigation is a way of emptying the lower bowel and is used to prevent faecal incontinence, or constipation, or simply as a method of bowel management.

With practice, the method is time saving and helps to give users independence and the confidence to enjoy activities such as swimming, gym and sleepovers, which they may have been reluctant to do in the past.

The booklets, which have been sponsored by Coloplast, have been written by ASBAH advisers Rosemary Batchelor, Lisa Raman, Paula Thompson and Gill Yaz.

The children's version is aimed at youngsters up to the age of 12 years, with the second booklet aimed at those 13 to 19 years.

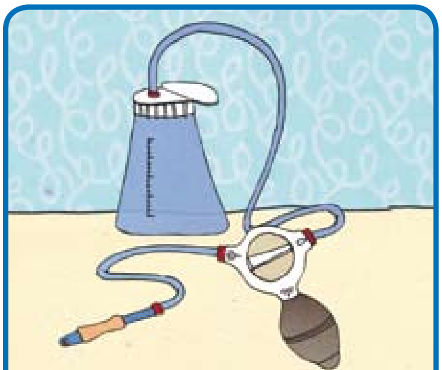
Rosemary Batchelor said: "Having child friendly literature to accompany the Peristeen Anal Irrigation system would appeal to young users and give them a better understanding of how and why it works, and so Perry and Tina were born.

"The other group that we felt were missing out on age specific information were the teens, so 'On the go' was written in language that they will relate to and will, hopefully, answer all the questions they are sure to have without them having to rely on mum and dad."

Sue Frost, Coloplast's, Medical Product Manager, told *Link:* "Coloplast is pleased to work with ASBAH and support these excellent booklets, which we hope will help children and teenagers understand more about Peristeen Anal Irrigation and give them the confidence to try this successful method of bowel management."

KEY POINT

- Bowel management information for children and teenagers
- Two new booklets from ASBAH in partnership with Coloplast



Peristeen Anal Irrigation is available on prescription but you can get further information by calling Charter Healthcare on 0800 132787. You can request a leaflet and DVD explaining more about the product.

ASBAH is grateful to Coloplast for sponsoring these books which is part of the campaign to increase awareness of bladder and bowel health.

Diary dates

Contact your regional office for more details on the following dates:

Eastern Region Local Association Forum Meeting

Date: Saturday 4 October 2008
Time: 11.00 am start
At: ASBAH House, 42 Park Road, Peterborough PE1 2UQ
Lunch and parking
Speaker: Colin Roberts, Fundraising Director
More information contact the Eastern Region Office on: 01733 421309

Suffolk / Norfolk Spina Bifida / Hydrocephalus Support Group

A group for adults with spina bifida and/or hydrocephalus and their carers meets every two months at Roydon Village Hall, High Road, Roydon, Nr Diss, Norfolk. Parents of teenagers with spina bifida and /or hydrocephalus are also very welcome.

For further details please contact Margaret & Alan Twyford on 01728 860916 or by email to ***twyfords@aandmtwyford.plus.com***

The following dates have been fixed so far:
10 July 2008 6.30-8.30 pm
11 September 2008 6.30-8.30 pm

ASBAH AGM 2008

Location: Leicester
Date: Wednesday 24 September 2008

A new venue and a new style. For more details please contact Lyn Rylance at ASBAH by calling 01733 421356 or email ***lynr@asbah.org***

Northern Region York Drop-in 2008

Low Moor Community Centre, Bray Road, Fulford, York YO 10 4JG
2nd Wednesday each Month - 10.15-12noon
9 July • 13 August • 10 Sept • 8 Oct
For further information please contact the Northern Region Office on 0113 255 6767 or email ***sylvieb@asbah.org***

Northern Region and North and West Yorkshire ASBAH Drop-In sessions.

Come and see us for coffee and a chat, meet with staff, volunteers and other service users and look at our information library. Children, family and friends are welcome too.

When: first Tuesday of every month
10am -12 noon
Where: ASBAH House North, 64 Bagley Lane, Farsley, Leeds. LS28 5LY
Tel: 0113 255 6767
email: nro@asbah.org

2008 Summer Experience

11-14 August
For further information please contact the Northern Region Office on 0113 255 6767 or email ***nro@asbah.org***

Your Voice presents:

Have Wheels Will Travel

Location: Leicester Marriott
Date: Friday 31 October 2008 to Sunday 2 November

Contact Barbara Robinson on ***barbarar@asbah.org*** or call 01733 421322 to book or reserve your place in this and any future Your Voice event.

Please e-mail the editor (Link@asbah.org) dates of your events for the next issue of Link by Friday 29 August 2008, giving the name of event, purpose, location, date, cost (if applicable), contact name, phone no. and email address.

Letters

We welcome letters for publication, which should be sent to: Editor, Link, 42 Park Road, Peterborough, PE1 2UQ. The editor reserves the right to edit letters, so please keep them short.

Holiday lets

When booking, check to make sure the accommodation suits your particular needs.

ISLE OF WIGHT ASBAH - HOLIDAY BUNGALOW

Wheelchair-accessible bungalow, sleeps six. Open-plan lounge/kitchen, wetroom. Site facilities. Local heated accessible pool. Beautiful area. Transport advisable.
Details and rates: Sylvia Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF
Tel: 01983 863658, *www.iwasbah.co.uk*

ROPERS WALK BARNS, MOUNT HAWKE, TRURO, CORNWALL

Single storey accessible barn converted to a high standard. Visit Britain Mobility Level 3A & 4* Quality ratings. Sleeps 4/6 + cot. Short level walk to village, close north coast, 8 miles Truro.
Details: Liz/Peter Pollard, tel. 01209 891632
Email: peterandliz@roperswalkbarns.co.uk
Web: *www.roperswalkbarns.co.uk*

PRESTATYN, NORTH WALES

An adapted caravan for disabled holiday makers. Sleeps 6 people (2 wheelchair accessible bedrooms), wheel-in shower with seat, open plan lounge, dining, kitchen area. Caravan has ramp access and is overlooking a children's play area in a site adjacent to the beach at Prestatyn – a small market town on the North Wales coast within easy travelling distance of Rhyl, Llandudno, and Snowdonia National Park. Costs are between £130-£350 per week for members and from £150-£425 per week for non-members; **for further information contact North & West Yorkshire ASBAH, c/o ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY Tel. 07989 2453994, e-mail** *nandwyasbah@aol.com*

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People with spina bifida are benefiting from the work of a pioneering clinic which, unusually, takes a holistic look at their healthcare.

Ann Wing:

London clinic leads the way

The multi-disciplinary clinic at London's Chelsea and Westminster Hospital attracts patients from around the country who are keen to see the small team of experts who can help with all their spina bifida-related health needs. Continence is one of the major problems.

It opens once a fortnight and patients can expect to be seen once a year for an annual MOT.

From an initial medial assessment, which may include a shunt x-ray, bladder scans and blood tests, patients can be helped in a number of areas. These include continence advice, occupational therapy and psychology, with access to other services such as gynaecology and neurology, ophthalmology and orthopaedics. It is hoped that soon urology will be added.

Ann Wing, continence nurse and clinic co-ordinator told *Link*: "I think we are the only clinic in the country to offer this complete service.

"Patients, who usually come to us through a referral from their GP, should expect to be here for most of the day.

"In the morning we do all the assessments, ultrasound scans and x-rays, then they will be seen by consultant Richard Morgan and the team, in the afternoon.

> **It is a long day for them but they do appreciate that it means all their needs are catered for on the day and in one place.**

"It is a long day for them but they do appreciate that it means all their needs are catered for on the day and in one place.

"Unlike the usual hospital appointments where everyone is given a ten minute slot, here our patients know that they have the time to talk through their problems. They are also provided with free drinks and a choice of sandwiches and fresh fruit for lunch."

The clinic was set up more than 20 years ago by paediatric consultant Mr Jeremy Lawson and Mr Duncan Forrest and was originally based at the Westminster Children's Hospital, where Ann was also working as a continence nurse.

They teamed up with Dr Richard Morgan at the Westminster Hospital and asked him to run an adolescent / adult spina bifida clinic.

When the Chelsea and Westminster Hospital was built 15 years ago on the site of the old St Stephen's Hospital, the clinic was able to move into spacious new surroundings, perfect for its needs.

Ann said: For many people with spina bifida their healthcare is fragmented and they have to visit different hospitals for their different needs. Here we look at the whole person and try to deal with everything."

KEY POINT

- **A small team of experts who can help with all spina bifida-related health needs**
- **Based at the Chelsea and Westminster Hospital**

Gill Yaz

ASBAH's continence adviser Gill Yaz, who attends the multi-disciplinary clinic, said: "Life with spina bifida is often complicated and, to us, it makes sense to address the challenges together, rather than in a piecemeal way.

The access to continence care is so important; at the clinic we know it really matters to get continence as good as it can be. I would like to see this model of care used all over the country, so everyone with spina bifida could access it. The clinic does fantastic work and is highly valued by the people who attend.'

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